

# Normative data for children and adolescents referred for specialist pain management in Australia

**EPPOC INFORMATION SERIES NO.2 2018**

## Publication details

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# Background

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The electronic Persistent Pain Outcomes Collaboration (ePPOC) is an Australasian initiative which aims to improve services and outcomes for people experiencing persistent pain. It is an initiative of the Faculty of Pain Medicine and was established in 2013 with funding from the NSW Ministry of Health.

The key functions of ePPOC are to:

- facilitate the collection of standardised data from pain management services
- analyse and report these data to participating pain services, stakeholders and the broader community
- use the data for benchmarking and quality improvement; and
- promote research into areas of importance in pain management.

While ePPOC was developed for adults experiencing persistent pain, PaedePPOC addresses the differing requirements of the paediatric pain management sector, allowing collection of data items and assessment tools specific to the needs of children, adolescents and their carers.

Further details regarding ePPOC and its establishment can be found in Tardif et al. (2017)<sup>1</sup> and on the ePPOC website at <https://ahsri.uow.edu.au/eppoc>

## Aims

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This paper aims to provide normative data for the PaedePPOC measures used by specialist paediatric pain management services. This information will provide a description of the children and adolescents referred for specialist pain management in Australia during the period from January 2014 to June 2018, allowing pain management services to compare scores for individuals seen at their service to these group values.

## Methods

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The analyses use information collected from patients aged between 5 and 18 years and their carers following referral to specialist paediatric pain management services in Australia.

## Results

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Data from 1071 episodes of care are included in this analysis, where both the child and their carer completed an ePPOC questionnaire at referral. This information was collected by seven specialist paediatric pain management services, located in New South Wales, Victoria and Queensland. The demographic characteristics and health profile of the patients at referral (as reported by the parent/carer) are shown in Table 1. Percentages are calculated as the proportion of stated responses.

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<sup>1</sup> H Tardif, C Arnold, C Hayes & K Eagar, 'Establishment of the Australasian Electronic Persistent Pain Outcomes Collaboration', *Pain Medicine*, vol. 18, no. 6, 2017, p.1007-1018.

**Table 1 – Characteristics of patients included in the analysis, N=1071**

<b>Gender, females, N (%)</b>	736 (68.7)
<b>Age in years, mean (SD)</b>	13.2 (2.6)
- Male	12.6 (2.6)
- Female	13.5 (2.5)
<b>Country of birth, N (%)</b>	
- Australia	963 (92.9)
- Other	74 (7.1)
<b>Aboriginal and/or Torres Strait Islander, N (%)</b>	45 (4.7)
<b>Current level of school, N (%)</b>	
- Preschool	4 (0.4)
- Primary school	343 (32.2)
- Secondary school	706 (66.4)
- Other	11 (1.0)
<b>Episode related to a compensation claim, N (%)</b>	27 (2.6)
<b>Main pain site, N (%)</b>	
- Back	173 (16.9)
- Abdomen	171 (16.7)
- Head or face	153 (15.0)
- Foot	109 (10.7)
- Knee	100 (9.8)
- Leg	96 (9.4)
- Hip	67 (6.5)
- Arm/shoulder	53 (5.2)
- Chest	43 (4.2)
- Other	58 (5.7)
<b>Patients experiencing pain more than 12 months, N (%)</b>	592 (56.2)
<b>Patients experiencing 'always present' pain, N (%)</b>	645 (79.0)
<b>Cause of pain (precipitating event), N (%)</b>	
- No known cause	420 (39.9)
- Injury	230 (21.9)
- Illness	167 (15.9)
- After surgery	76 (7.2)
- Other	159 (15.1)
<b>Health problems and disabilities, N (%)</b>	
- Mental health condition	265 (24.7)
- Chronic disease	234 (21.8)
- Cancer (now or in the past)	22 (2.1)
- Physical disability	81 (7.6)
- Sight impairment	72 (6.7)
- Intellectual disability	24 (2.2)
- Hearing impairment	22 (2.1)
<b>Medication – daily use, N (%)</b>	
- Opioid (with and without codeine)	85 (7.9)
- Paracetamol	310 (31.0)
- Anti-inflammatory	241 (22.3)
- Alternative/complementary	172 (18.1)
- Medication for neuropathic pain	312 (32.5)

Pain management services participating in PaedePPOC collect a standard minimum dataset consisting of demographic and clinical data items, and standardised assessment tools. The assessment tools used in PaedePPOC are:

- Faces of Pain Scale – Revised (for patients aged 5-7 years)<sup>2</sup>
- Brief Pain Inventory – pain intensity questions (for patients 8-18 years)<sup>3</sup>
- Pediatric Quality of Life Inventory (for patients aged 5-18 years)<sup>4</sup>
- Functional Disability Index (for patients aged 8-18 years)<sup>5</sup>
- Bath Adolescent Pain Questionnaire, Section 5 – pain-related worry (for patients aged 13-18 years)<sup>6</sup>.

Tables 2-5 show the mean, standard deviation and interquartile range for each of the assessment tools, reported by the patient at referral. Scores are reported for the total group of patients, males and females and by age group. Figures 1-9 provide a graphical representation of the mean scores for the total group, males and females and by age group.

Note that there are only a small number of children in the 5 to 7 year age group. The data for these children are included for completeness, however scores for this group should be interpreted with caution.

## Practice points

- Most pain services utilise patient-reported outcome measures to guide triage and treatment
- Normative data can assist clinicians interpret patient-reported measures, providing a reference point to gauge symptom severity
- The information in the following tables can help to determine, for example, whether an individual's scores are typical, high or low compared to other paediatric patients referred for specialist pain management in Australia
- In the following tables:
  - the mean score shows the average score on each assessment tool for all patients at referral, by age group and for males and females
  - the interquartile range indicates where 50% of patient scores lie – a score above or below this range suggests that the patient is in the top 25% or bottom 25% of the population in terms of symptom severity on the measure.

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<sup>2</sup> Faces Pain Scale – Revised, © 2001, International Association for the Study of Pain

<sup>3</sup> Modified Brief Pain Inventory, © 1991. Reproduced with acknowledgement of the Pain Research Group, University of Texas, MD Anderson Cancer Centre, USA

<sup>4</sup> Paediatric Quality of Life Inventory (PedsQL™), © 1998 JW Varni, Ph.D. All rights reserved.

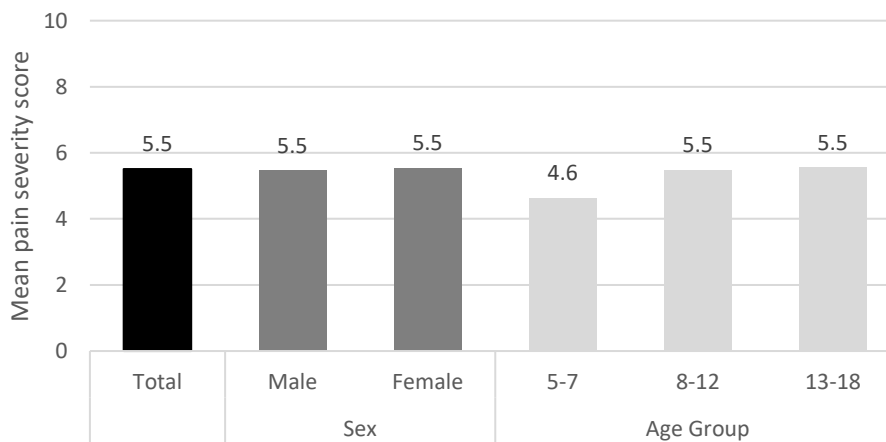
<sup>5</sup> LS Walker & JW Greene, 'The Functional Disability Inventory (FDI): Measuring a neglected dimension of child health status', *Journal of Paediatric Psychology*, vol. 16, no. 1, 1991, p. 39-58.

<sup>6</sup> C Eccleston, A Jordan, LM McCracken, M Sled, H Connell & J Clinch, 'The Bath Adolescent Pain Questionnaire (BAPQ): Development and preliminary psychometric evaluation of an instrument to assess the impact of chronic pain on adolescents', *Pain* vol. 118, no. 1, 2005, p.263-270.

**Table 2. Pain severity – mean, standard deviation (SD) and interquartile range for all patients, males and females and by age group**

	Total	Sex		Age group		
		Male	Female	5-7	8-12	13-18
<b>Pain severity</b>						
Mean (SD)	5.5 (2.0)	5.5 (2.1)	5.5 (1.9)	4.6 (2.0)	5.5 (2.2)	5.5 (1.9)
Interquartile range	4.3 – 7.0	4.0 – 7.0	4.3 – 7.0	3.8 – 6.0	4.0 – 7.0	4.3 – 7.0
Number	1047	330	717	10	308	729
<b>Worst pain</b>						
Mean	7.7 (2.0)	7.7 (2.1)	7.7 (1.9)	8.1 (2.6)	7.7 (2.2)	7.7 (1.8)
Interquartile range	7.0 – 9.0	7.0 – 9.0	7.0 – 9.0	7.0 – 10.0	7.0 – 9.0	7.0 – 9.0
Number	1056	332	724	10	312	734
<b>Least pain</b>						
Mean	3.6 (2.4)	3.5 (2.6)	3.6 (2.3)	2.3 (2.8)	3.5 (2.6)	3.6 (2.3)
Interquartile range	2.0 – 5.0	1.0 – 5.0	2.0 – 5.0	0.0 – 6.0	1.0 – 5.0	2.0 – 5.0
Number	1053	331	722	10	310	733
<b>Average pain</b>						
Mean	5.7 (2.2)	5.7 (2.3)	5.7 (2.1)	5.1 (3.0)	5.7 (2.4)	5.7 (2.0)
Interquartile range	4.0 – 7.0	4.0 – 7.0	4.0 – 7.0	4.0 – 8.0	4.0 – 7.0	4.0 – 7.0
Number	1051	331	720	10	309	732
<b>Pain now</b>						
Mean	5.1 (2.8)	5.0 (2.9)	5.2 (2.7)	3.3 (3.1)	4.9 (3.1)	5.2 (2.6)
Interquartile range	3.0 – 7.0	3.0 – 7.0	3.0 – 7.0	0.0 – 6.0	2.0 – 7.0	3.0 – 7.0
Number	1054	332	722	11	311	732

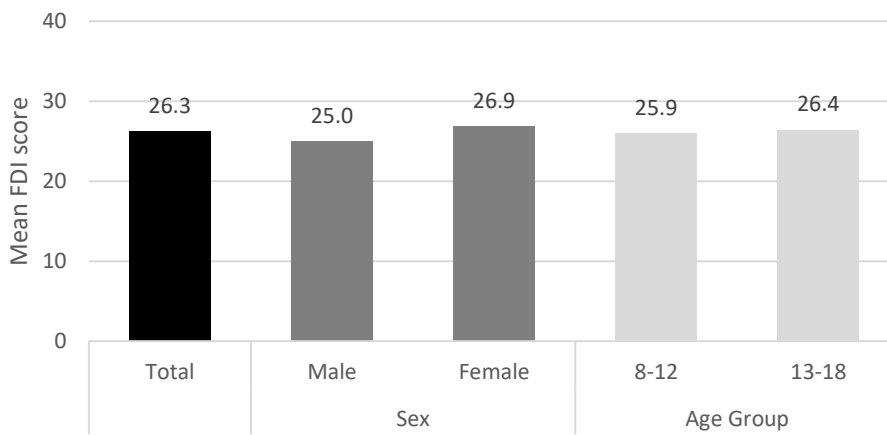
Figure 1: Pain Severity



**Table 3. Functional Disability Inventory – mean, standard deviation (SD) and interquartile range for all patients, males and females and by age group**

	Total	Sex		Age group		
		Male	Female	5-7	8-12	13-18
Mean (SD)	26.3 (12.0)	25.0 (13.0)	26.9 (11.5)	n/a	25.9 (12.1)	26.4 (12.0)
Interquartile range	17.0 – 35.0	15.0 – 35.0	19.0 – 35.0	n/a	17.0 – 35.0	17.0 – 35.0
Number	1029	321	708	0	298	731

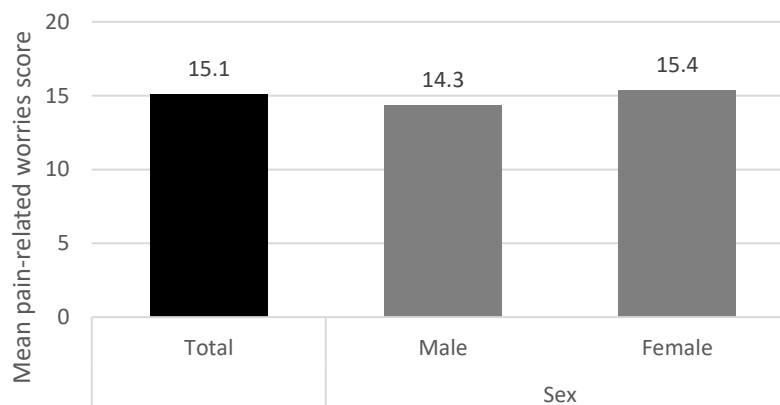
Figure 2: Functional Disability



**Table 4. Bath Adolescent Pain Questionnaire – pain-related worries subscale. Mean, standard deviation (SD) and interquartile range for all adolescent patients and by sex**

	Total	Male	Female
Mean (SD)	15.1 (6.1)	14.3 (6.2)	15.4 (6.1)
Interquartile range	11.0 – 19.0	11.0 – 19.0	11.0 – 19.0
Number	624	167	457

Figure 3: Pain-related worries



**Table 5. Pediatric Quality of Life – mean, standard deviation (SD) and interquartile range for all patients, males and females and by age group\*.**

	Total	Sex		Age group		
		Male	Female	5-7	8-12	13-18
<b>Physical</b>						
Mean (SD)	39.7 (22.4)	43.5 (24.6)	37.9 (21.1)	51.4 (20.0)	40.1 (23.7)	39.3 (21.8)
Interquartile range	21.9 – 56.3	25.0 – 59.4	21.9 – 50.0	43.8 – 75.0	21.9 – 56.3	21.9 – 53.1
Number	1044	328	716	9	309	726
<b>Emotional</b>						
Mean	49.8 (22.9)	53.4 (23.9)	48.2 (22.3)	43.9 (33.3)	49.6 (22.4)	50.0 (23.0)
Interquartile range	35.0 – 65.0	35.0 – 70.0	30.0 – 65.0	30.0 – 60.0	30.0 – 65.0	35.0 – 65.0
Number	1043	327	716	9	308	726
<b>Social</b>						
Mean	65.5 (22.8)	67.5 (21.8)	64.5 (23.2)	56.7 (25.5)	65.6 (21.2)	65.5 (23.4)
Interquartile range	50.0 – 80.0	55.0 – 85.0	50.0 – 80.0	40.0 – 60.0	55.0 – 80.0	50.0 – 85.0
Number	1040	326	714	9	307	724
<b>School</b>						
Mean	47.9 (22.9)	50.3 (22.5)	46.8 (23.0)	61.1 (19.6)	52.7 (21.7)	45.7 (23.1)
Interquartile range	30.0 – 65.0	35.0 – 65.0	30.0 – 65.0	50.0 – 70.0	35.0 – 70.0	30.0 – 60.0
Number	1042	327	715	9	308	725
<b>Psychosocial</b>						
Mean	54.4 (18.4)	57.0 (18.4)	53.2 (18.3)	53.8 (23.5)	55.9 (17.8)	53.7 (18.6)
Interquartile range	42.0 – 68.0	45.0 – 70.0	42.0 – 67.0	48.0 – 70.0	45.0 – 68.0	42.0 – 67.0
Number	1045	328	717	9	309	727
<b>Total</b>						
Mean	49.3 (17.7)	52.3 (18.2)	47.9 (17.3)	53.0 (16.9)	50.4 (17.3)	48.7 (17.9)
Interquartile range	37.0 – 60.9	40.2 – 65.2	35.9 – 59.8	43.5 – 67.4	39.1 – 60.9	35.9 – 60.9
Number	1045	328	717	9	309	727

\*Note that higher scores reflect better quality of life

Figure 4: PedsQL Physical

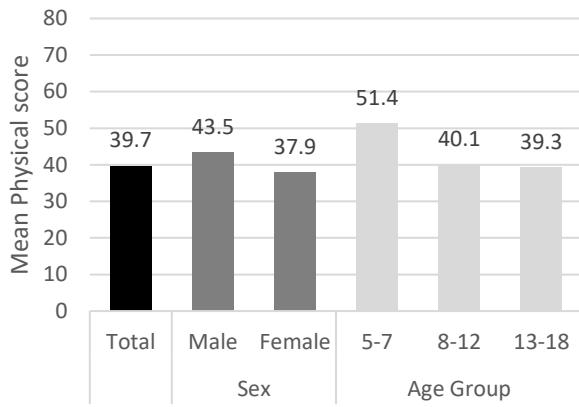


Figure 5: PedsQL Emotional

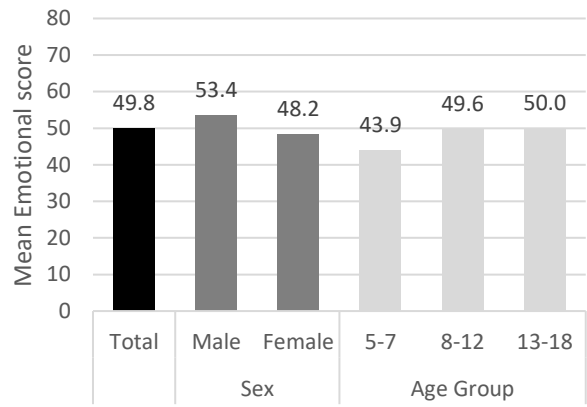


Figure 6: PedsQL Social

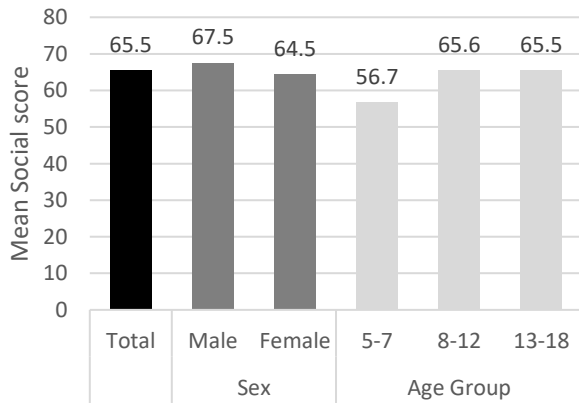


Figure 7: PedsQL School

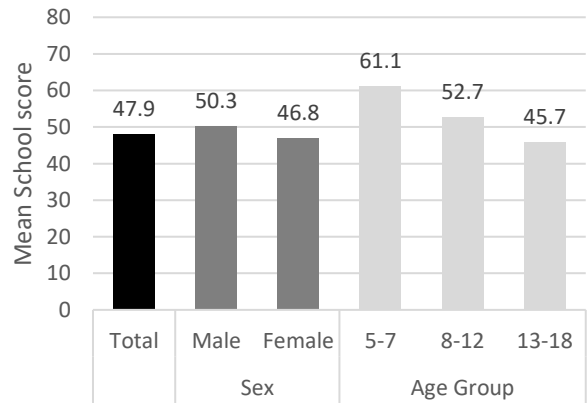


Figure 8: PedsQL Psychosocial

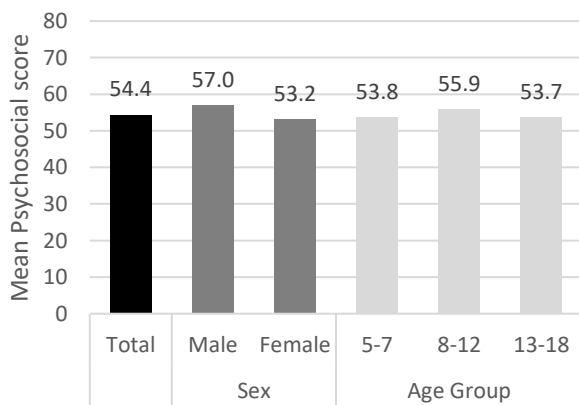
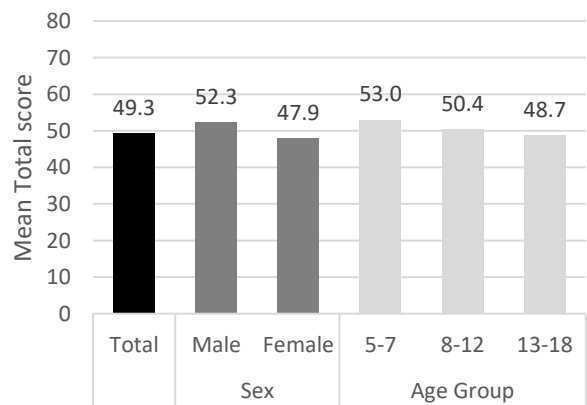


Figure 9: PedsQL Total





# Series List

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No.1 2018: *Normative data for patients referred for specialist pain management in Australia*

No.2 2018: *Normative data for children and adolescents referred for specialist pain management in Australia*